



editorial

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A helping hand: providing information to patients and the public

Knowledge is power. It may be a cliché; but lack of knowledge about mental illness results in powerlessness, fear, secrecy, shame and stigma. We need to give patients opportunities to make educated choices. Not just choices about when and by whom they are seen, but also informed choices about which treatment they would like. For example, would a working mother with depression prefer cognitive-behavioural therapy, a selective serotonin reuptake inhibitor, or a combination of the two? Patient expectations have changed. Long gone are the days of 'doctor knows best'. Most patients would like us to consider their preferences and many want to be involved in decisions about their care (Coulter *et al*, 1999). They want to be consumers and service users rather than passive recipients of treatment. In today's society, patients may be more likely to see doctors as one of a range of service providers. However, no amount of politically correct re-badging will change a simple fact: a person kept ignorant of what is wrong and what is going to happen is hardly in a position to be an active consumer. Without choice, people remain passive. 'It is our choices that show what we truly are,' said Dumbledore to Harry Potter (Rowling, 1999). Yet – unlike wizards – psychiatrists do not always get it right.

How can patient preferences be incorporated into clinical decisions? We cannot expect patients to make meaningful choices without access to high-quality, evidence-based information, presented in a way that they can read and understand. This sort of patient information is useful for enabling patients to make choices about treatment, debunking myths and emphasising facts. It can also help prevent relapse, motivate patients to take better care of themselves, improve the quality of consultations, help carers understand what is going on, identify self-help groups and other sources of information, and instil hope. Many patients have tried to find such information, and have been disappointed where this has been lacking (Audit Commission, 1993). More recently, the Consumers' Association published a report demonstrating that patients are often dissatisfied with the health information they receive (Consumers' Association, 2003).

The College's Public Education Committee Editorial Sub-Committee aims to fill the void between demand and availability of health information, by producing public

information leaflets. Sadly, not everyone is enthusiastic about sharing information with patients (Coulter, 1997). Some have suggested that most patients do not want to take an active role in decisions about their care. This is not new; even 20 years ago, Strull *et al* (1984) found that clinicians underestimated patients' desire for information. Others are reluctant to inform patients about their prognosis, perhaps afraid of causing harm. A minority may worry that educated patients are more likely to demand evidence-based but expensive therapies or drugs, threatening the already precarious balance of rationing treatment.

In the words of Edward H. Goodman (1879), 'it is a distinct art to talk medicine in the language of a non-medical man'. Unfortunately, many patient information leaflets lack this art. In others, information about efficacy and suitability of different treatments is not included. Patients are increasingly conducting their own research online and the varying quality of this information is a cause for concern. A number of websites contain health hoaxes or misinformation. The Editorial Sub-Committee, however, offers something unique. The 'Help is at Hand' series is regularly updated in the light of new clinical research evidence, political developments and web feedback. Unlike leaflets written by special interest groups, charities and pressure groups who 'have their own drums to beat' (Kennedy, 2003), they are written by jobbing psychiatrists, in close collaboration with a wide range of specialists and experts, rather than by an out-of-touch clique in an academic citadel or a single-issue pressure group dominated by a strong individual who has an agenda for all based on limited experience. They are specific about the purpose of their information and intended audience. Leaflets are piloted through the Patients' and Carers' Liaison Group. 'Help is at Hand' leaflets have the potential to bring psychiatrists and patients together to improve the quality of consultations and other communication in a language that both can understand.

In this issue of the *Bulletin*, Timms and colleagues describe their evaluation of 'Help is at Hand' on the College website (Timms *et al*, 2004, this issue). Clearly, many have accessed 'Help is at Hand' information online and found it useful. The leaflets have, on the whole, been



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extremely well received. Those who responded to the feedback questionnaire might have been patients, carers, family members, health professionals or students; a new feedback question has been introduced to establish the respondents' identity.

There are some disadvantages inherent in producing patient information in written format only. Leaflets are neither universally acceptable nor accessible. Seven million adults in the UK have poor basic literacy skills (Working Group on Post-School Basic Skills, 1999); they would benefit from audio formats and increased use of pictorial information. The many blind or partially sighted people in the UK are currently unable to access 'Help is at Hand'. However, exciting developments are in the pipeline. The Editorial Sub-Committee is looking at a range of ways to make information more accessible to all.

The disadvantage of paper-based information is that it can quickly look tired and dated, as advertising and publicity material becomes ever more attention-seeking, cryptic and colourful. Once distributed, outdated and obsolete leaflets are difficult to recall. To lessen this problem members and administrative staff need to be vigilant, developing systems ensuring that out-of-date leaflets are weeded out of leaflet racks and replaced by updated stock.

The College's patient information leaflets help us do our work even when we cannot be there. Next time you

want to direct patients to good-quality mental health information, remember – 'Help is at Hand'.

References

- AUDIT COMMISSION (1993) *What Seems to be the Matter: Communication Between Hospitals and Patients*. London: HMSO.
- CONSUMERS' ASSOCIATION (2003) *Patient Information: What's the Prognosis*. London: Consumers' Association.
- COULTER, A. (1997) Partnerships with patients: the pros and cons of shared clinical decision-making. *Journal of Health Services Research Policy*, **2**, 112–121.
- COULTER, A., ENTWISTLE, V. & GILBERT, D. (1999) Sharing decisions with patients: is the information good enough? *BMJ*, **318**, 318–322.
- KENNEDY, J. G. (2003) 'Doc, tell me what I need to know' – a doctor's perspective. *BMJ*, **327**, 862–863.
- ROWLING, J. K. (1999) *Harry Potter and The Chamber of Secrets*. London: Bloomsbury.
- STRULL, W. M., LO, B. & CHARLES, G. (1984) Do patients want to participate in medical decision making? *JAMA*, **252**, 2990–2994.
- TIMMS, P., BRISCOE, M., HART, D., et al (2004) 'Help is at Hand' on the web – what do our readers think? *Psychiatric Bulletin*, **28**, 24–27.
- WORKING GROUP ON POST-SCHOOL BASIC SKILLS (Chairman, Sir Claus Moser) (1999) *A Fresh Start: Improving Literacy and Numeracy*. London: Department for Education and Employment.
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